



THE ACCESS AND  
DELIVERY PARTNERSHIP

*New Health Technologies for TB, Malaria and NTDs*

# DISCUSSION PAPER

## THE GENDER DIMENSIONS OF NEGLECTED TROPICAL DISEASES



*Empowered lives.  
Resilient nations.*

**COUNTDOWN**  
Calling time on Neglected Tropical Diseases

**TDR** For research on  
diseases of poverty  
UNICEF • UNDP • World Bank • WHO



From the People of Japan



# DISCUSSION PAPER

## THE GENDER DIMENSIONS OF NEGLECTED TROPICAL DISEASES

HIV, Health and Development Group  
Bureau for Policy and Programme Support  
United Nations Development Programme

NOVEMBER 2019



*Empowered lives.  
Resilient nations.*



From the People of Japan



# TABLE OF CONTENTS

<b>Acknowledgements</b> .....	<b>iii</b>
<b>Acronyms</b> .....	<b>iv</b>
<b>Overview</b> .....	<b>1</b>
<b>SECTION 1: Understanding the impacts of sex and gender on Neglected Tropical Disease risk and outcomes</b> .....	<b>3</b>
Epidemiology.....	5
Case study of urogenital schistosomiasis .....	7
Changing contexts matter.....	9
<b>SECTION 2: Recommendations for addressing Neglected Tropical Disease-related gender inequities</b> .....	<b>11</b>
Recommendation 1: Account for how sex- and gender-related divisions of labour, everyday practices, social norms and beliefs within and beyond the household impact Neglected Tropical Disease risk.....	11
Recommendation 2: Account for how sex and gender impact the accessibility and acceptability of treatment.....	12
Recommendation 3: Address sex- and gender-related stigma and mental health impacts of Neglected Tropical Diseases.....	15
Recommendation 4: Collect and use sex- and gender-disaggregated data and implementation research to continuously improve Neglected Tropical Disease programming and ensure equity .....	16
Recommendation 5: Take a health systems approach that promotes intersectoral processes and puts community engagement at the centre of Neglected Tropical Disease programmes.....	17
<b>Conclusion</b> .....	<b>19</b>
.....	
<b>Appendix 1: Applying a gender framework to understand how gender as a power relation and driver of inequality affects exposure, risk of transmission, prevention and treatment of Neglected Tropical Diseases</b> .....	<b>20</b>
<b>References</b> .....	<b>21</b>



## ACKNOWLEDGEMENTS

This discussion paper was authored by Kim Ozano, Laura Dean, Eleanor MacPherson and Sally Theobald from the COUNTDOWN consortium at the Liverpool School of Tropical Medicine, Mami Yoshimura and Natalia Linou from UNDP and Christine Halleux, Mariam Otmani del Barrio and Olumide Ogundahunsi from TDR (UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases). The paper benefited enormously from contributions by Tenu Avafia, Roy Small, Kenechukwu Esom, Justus Eisfeld, Kazuyuki Uji and Mashida Rashid from UNDP. The paper was commissioned and published by the UNDP-led Access and Delivery Partnership and funded by the Government of Japan.

# ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
CDD	community drug distributor
DALY	disability-adjusted life year
FGS	female genital schistosomiasis
HIV	Human Immunodeficiency Virus
MDA	mass drug administration
MGS	male genital schistosomiasis
NTD	neglected tropical disease
SDGs	Sustainable Development Goals
UNDP	United Nations Development Programme
WHO	World Health Organization



# OVERVIEW

Neglected Tropical Diseases (NTDs) are a group of parasitic and bacterial diseases that cause illness, long-term disability and death for billions of people across 149 countries. NTDs affect the world's poorest and most marginalized people,<sup>[1-3]</sup> deepening and perpetuating poverty and inequality by reducing the ability of individuals to earn a living and limiting productivity in the workplace.<sup>[4,5]</sup> The Sustainable Development Goals (SDGs) recognize the elimination of NTDs as a target for global action. In line with the ambitions of the SDGs and its pledge to 'leave no one behind,' it is important to integrate NTD activities and interventions into broader health systems. NTDs are found in tropical and subtropical conditions, mostly affecting those without access to adequate water and sanitation and those who have increased contact with infectious vectors and domestic animals and livestock<sup>[4]</sup> due to their livelihoods or domestic activities. Of the many NTDs, the World Health Organization (WHO) lists 20 diseases as its priority list of NTDs.<sup>[4]</sup> This discussion paper focuses on the below two broad groups of NTD classification.

- **NTDs targeted by preventive chemotherapy:** These are NTDs that can be treated through mass drug administration (MDA) of preventive chemotherapy medicines and transmission control. Preventative chemotherapy NTDs include **dracunculiasis, lymphatic filariasis, onchocerciasis, schistosomiasis, soil-transmitted helminths** and **trachoma**. Medicines are mostly donated by biomedical companies with distribution assisted by non-governmental development organizations in partnership with government health systems in endemic countries, with bilateral support usually from the governments of the United Kingdom and the United States.<sup>[1]</sup> Diseases such as lymphatic filariasis and schistosomiasis often require case management in which preventative chemotherapy control does not reach all patients.
- **NTDs targeted by Innovative and Intensified Disease Management:** These are NTDs for which cost-effective control tools do not exist and/or for which large-scale use of existing tools is limited. Innovative and Intensified Disease Management diseases include **leprosy, Buruli ulcer, Chagas disease, human African trypanosomiasis, leishmaniasis** and **yaws**. Innovative and Intensified Disease Management NTDs are difficult and costly to manage and their burden on those affected is poorly understood as relatively lower investments have been made in research and development as well as treatment programmes. People affected often live in remote rural areas with limited access to diagnosis and treatment.<sup>[4]</sup> Where treatment is prioritized, it often focuses on the medical management of disease and ignores broader psycho-social components.<sup>[5]</sup>

Gender, sex and their intersections with other social determinants of health shape peoples' vulnerability to and experience of NTDs, as well as their ability to access care and treatment.<sup>[6,7]</sup> Understanding similarities and differences in how people of all genders and sexes, including women and girls, are vulnerable to and experience NTDs can support governments, international and national partners and researchers to accelerate responses to NTDs and deliver equitable prevention, diagnosis and treatment services. Rapidly changing environmental and political contexts due to conflict, climate change, urbanization and migration affect levels of infection for people of different genders. These contexts can also impact health care-seeking behaviour and delivery of prevention and treatment programmes.

In line with the UNDP Strategic Plan 2018–2021 and the HIV, Health and Development Strategy 2016–2021, this discussion paper explores the gender dimensions of NTDs. It reviews the available evidence of how gender impacts NTD risks and outcomes, highlighting existing data and implementation gaps. The paper draws upon a detailed case study of urogenital schistosomiasis that illustrates how researchers and NTD programmes can undertake a gender-informed analysis to ensure inequalities are not exacerbated as contexts shift. The paper proposes a set of five recommendations as a way forward to better understand and act on the gender dimensions of NTDs. In this way, the paper aims to support efforts to reduce the global impact of NTDs and support countries to reach the targets of the WHO Roadmap on NTDs by 2020 and contribute to the attainment of universal health coverage by 2030.<sup>[3, 8]</sup>

### **Box 1: Neglected Tropical Diseases and the Sustainable Development Goals**

SDG 3, ensuring healthy lives and promoting well-being for all at all ages, includes a target to end the epidemic of NTDs by 2030 (SDG Target 3.3) with progress measured by the number of people requiring NTD interventions. However, the control and elimination of NTDs also contribute to other Sustainable Development Goal ambitions, including those on poverty (SDG 1), education (SDG 4), gender equality (SDG 5), clean water and sanitation (SDG 6), decent work and economic growth (SDG 8) and inequalities (SDG 10). As NTDs affect the most disadvantaged and hard to reach populations, often without access to quality health services, they are considered a litmus test for universal health coverage and an equity 'tracer'.<sup>[1, 2, 9]</sup>

NTDs perpetuate the cycle of poverty through direct costs associated with diagnosis and treatment as well as indirect costs associated with lost educational potential, reduced economic productivity, caregiving responsibilities and stigma.<sup>[10]</sup> Direct healthcare costs include formal and informal healthcare fees, cost of medicines and tests, travel, food and accommodation.<sup>[11, 12]</sup> Out-of-pocket costs for treatment and care often result in catastrophic financial loss for families, as found in Ghana and Nigeria.<sup>[12, 13]</sup> These are also indirect costs associated with health care. NTDs can also have a significant impact on development and productivity. Lymphatic filariasis, for example, is associated with an economic loss of US\$1 billion annually in India alone.<sup>[14]</sup> Morbidity, disability and stigma associated with NTDs result in missed days of work for adults, which impacts the whole family.<sup>[12, 15]</sup> A study summarizing data from countries with known or suspected blinding trachoma found that for women in the poorest regions of the world, blindness and visual impairment from trachoma forgoes \$2 billion per year in potential country productivity across affected countries.<sup>[16]</sup>

### **Box 2: Gender, Neglected Tropical Diseases and poverty**

Severe infections can also impair physical and cognitive development, with micronutrient deficiencies and other symptoms leading to poor school performance and absenteeism. For example, illness from schistosomiasis has been linked to decreased school attendance and substantial reductions in future earnings,<sup>[17]</sup> while also affecting cognitive development of young children and reducing learning opportunities.<sup>[18]</sup> Furthermore, girls from households with individuals infected with onchocerciasis and other NTDs, especially those that result in blindness and skin disease, are more at risk of receiving less education as they are often required to care for the family member.<sup>[19, 20]</sup>

The potential co-benefits to health, education, gender equality and poverty alleviation of NTD prevention and treatment are clear. A ten-year study investigating the impact of school-based treatment for NTDs in Kenya found that boys stayed enrolled for more years of primary school, worked 17 percent more hours each week and missed one less meal per week.<sup>[21]</sup> The same study showed girls being approximately 25 percent more likely to have attended secondary school, thus halving the gender education gap.<sup>[21]</sup>

# SECTION 1: UNDERSTANDING THE IMPACTS OF SEX AND GENDER ON NEGLECTED TROPICAL DISEASE RISK AND OUTCOMES

NTDs disadvantage people of different genders, including women and girls, in different ways, depending on context and individual health status. Environmental and structural factors, including sub-standard living conditions and a lack of safe water and sanitation, intersect with biological, social, economic and cultural factors to shape vulnerability to and experiences of NTDs. Understanding how sex and gender intersect with key social determinants, such as poverty, education and livelihoods, is essential to ensure no one is left behind in the fight against NTDs.

**What is 'sex?'** 'Sex' constitutes the biological characteristics (including genitals, gonads and chromosome patterns) that are attributed to male, female or intersex bodies.<sup>1</sup> Different anatomies and immune responses that affect exposure to NTDs, how they manifest, their intensity and treatment vary by sex.<sup>[22]</sup> In females, symptoms can be seen in the reproductive system, genitalia, breasts (lymphedema), menstruation, pregnancy and childbirth.<sup>[23]</sup> NTDs can impair reproductive health, cause infertility, increase risk for sexually transmitted infections and can cause anaemia and high maternal morbidity and mortality rates<sup>[20]</sup> (see Box 3). For some NTDs, for example onchocerciasis, sexed hormonal differences have been suggested to account for relatively higher resistance to infection of females relative to males.<sup>[24]</sup> For males, NTDs can manifest in the genitalia and have implications for reproductive and sexual health and in the case of schistosomiasis presents the long term risk of bladder cancer. For example, lymphatic filariasis can develop into chronic lymphedema and hydrocele of the scrotum leading to social stigma and loss of earning opportunities.<sup>[25]</sup>

**What is 'gender?'** WHO defines 'gender' as "the socially constructed characteristics of women and men – such as norms, roles and relationships of and between groups of women and men. It varies from society to society and can be changed. While most people are born either male or female, they are taught appropriate norms and behaviours – including how they should interact with others of the same or opposite sex within households, communities and work places. When individuals or groups do not 'fit' established gender norms they often face stigma, discriminatory practices or social exclusion – all of which adversely affect health. It is important to be sensitive to different identities that do not necessarily fit into binary male or female sex categories."<sup>[26]</sup> Transgender people have a gender identity that is different from the sex that they were assigned at birth.<sup>2</sup> In general, the differences in NTD infection rates between men and women in most endemic areas are not due to the biological differences, or 'sex,' but instead related to 'gender' – labour allocation, social practices and roles associated with being a man, woman, girl, boy or other gender.<sup>[27]</sup> This is because people can have different susceptibilities to disease that interact daily with social, economic and cultural gender-specific contextual variations.<sup>[28]</sup> For example, increased reinfection rates of schistosomiasis for fishermen in Uganda were due to variations in parasitic exposure, as opposed to biological differences in susceptibility to infection. Health outcomes for transgender<sup>3</sup> people are generally poorer than for cisgender (i.e. not transgender) men and women.<sup>4</sup>

---

<sup>1</sup> Intersex people are born with physical sex characteristics that don't fit medical and social norms for female or male bodies (<https://ihra.org.au/18106/what-is-intersex/>).

<sup>2</sup> Office of the United Nations High Commissioner for Human Rights, United Nations Free & Equal Transgender Fact Sheet, 2017 ([www.unfe.org/wp-content/uploads/2017/05/UNFE-Transgender.pdf](http://www.unfe.org/wp-content/uploads/2017/05/UNFE-Transgender.pdf)).

<sup>3</sup> Transgender people are people whose gender identity or expression differs from the sex they were assigned at birth.

<sup>4</sup> See, for example: [https://www.ajpmonline.org/article/S0749-3797\(18\)31870-1/fulltext](https://www.ajpmonline.org/article/S0749-3797(18)31870-1/fulltext) and <https://www.pcori.org/research-results/2013/examining-health-outcomes-people-who-are-transgender>.

### Box 3: Neglected Tropical Diseases and pregnancy

SDG 5 aims to tackle gender inequality worldwide, which deprives women and girls of their basic rights and opportunities, including universal access to sexual and reproductive health. While NTDs impose a heavy burden on all sexes, there has been increasing recognition of the disproportionate impact of some NTDs on the health of girls and women, particularly female genital schistosomiasis (FGS).<sup>[13]</sup> The outcomes linked to FGS, such as infertility, anaemia, low birth weight infants and an increased infant and maternal mortality rate, have severe physical, psycho-social and economic consequences that reduce opportunities to achieve gender equality.<sup>[29, 30]</sup> In 2002, WHO reported that women living in schistosomiasis endemic areas may spend up to 25 percent of their reproductive years pregnant and another 60 percent of this time lactating.<sup>[31, 32]</sup> Thus, women who miss treatment due to pregnancy and breastfeeding are likely to repeatedly miss treatment and may be more susceptible to organ damage and cancer due to chronic schistosomiasis.<sup>[31]</sup> Pregnant and lactating women are still mostly excluded from MDA treatment campaigns for schistosomiasis due to safety concerns, even though the treatment was recommended for pregnant women by WHO in 2002.<sup>[20, 33]</sup> Deworming during pregnancy has demonstrated reduced maternal morbidity and mortality, leading to calls for including deworming in ante/postnatal packages in hookworm endemic areas in low and middle income countries.<sup>[20]</sup>

Other NTDs, such as lymphatic filariasis and onchocerciasis, cannot be safely treated in pregnant women, thus leaving them at risk of infection.<sup>[34]</sup> This has impacts not only on the mother but also on their babies as women with onchocercal skin disease have reported reducing the period they breastfeed due to itching.<sup>[19]</sup> Safety testing of ivermectin and diethylcarbamazine in pregnancy or during lactation is needed to ensure that all women in their reproductive years may become eligible for MDA treatment programmes for lymphatic filariasis and onchocerciasis, as well as for integrated control against all of the most common NTDs.<sup>[20]</sup>

Other negative health outcomes from NTDs before and during pregnancy include increased vulnerability to anaemia (menstruation causes low iron reserves), low iron intake and additional demands for iron from the fetus.<sup>[35]</sup> Pregnant women in resource-poor settings are at added risk of hookworm anaemia which is further compounded by co-infections from malaria.<sup>[35]</sup> Malaria is a leading cause of anaemia in pregnant woman and young children and NTD co-infections worsen anaemia, potentially leading to large numbers of maternal deaths during pregnancy and to premature births.<sup>[36]</sup> Intergenerational effects also exist. Lymphatic filariasis in pregnant women can increase susceptibility in infants and children to filarial infection even if the mother has previously participated in several years of MDA treatment.<sup>[37]</sup>

Consideration of how pregnant and breastfeeding women can be better protected against NTDs to address current inequities in NTD treatment protocols is needed. Health professionals need to understand the implications of having an NTD before and during pregnancy. Advocacy and health education campaigns for NTDs must ensure that people of all genders are made aware of NTD signs and symptoms and are empowered to seek health services early.<sup>[38]</sup> NTD programmes could facilitate this by educating and engaging with other health sectors, particularly programmes and health professionals from maternal and child health services who can provide information and education to girls and women about NTD prevention, treatment and risk.<sup>[39]</sup> Current NTD policies limit treatment for pregnant women during and post pregnancy despite some drugs having been deemed safe for use in this period. Different treatment approaches must be developed to ensure that all who are pregnant can access needed treatment. If people are excluded during pregnancy due to legitimate safety concerns, efforts to treat them when it is safe should be built into MDA campaigns for NTDs.

## EPIDEMIOLOGY

Understanding the epidemiology of NTDs, including differences by sex, is a critical first step. Table 1 presents data from the Global Burden of Disease Study in 2013,<sup>[41]</sup> reflecting a total of 2.3 billion cases of WHO prioritized NTDs.<sup>[41]</sup> Soil-transmitted helminths account for 1.75 billion cases, comprising more than three-quarters of all prevalent NTD infections. Also, highly prevalent are schistosomiasis, foodborne trematodiasis, lymphatic filariasis and onchocerciasis. NTDs are most prevalent in Sub-Saharan Africa and the Asia-Pacific regions.

**Table 1: Data from the Global Burden of Disease Study (2013)**

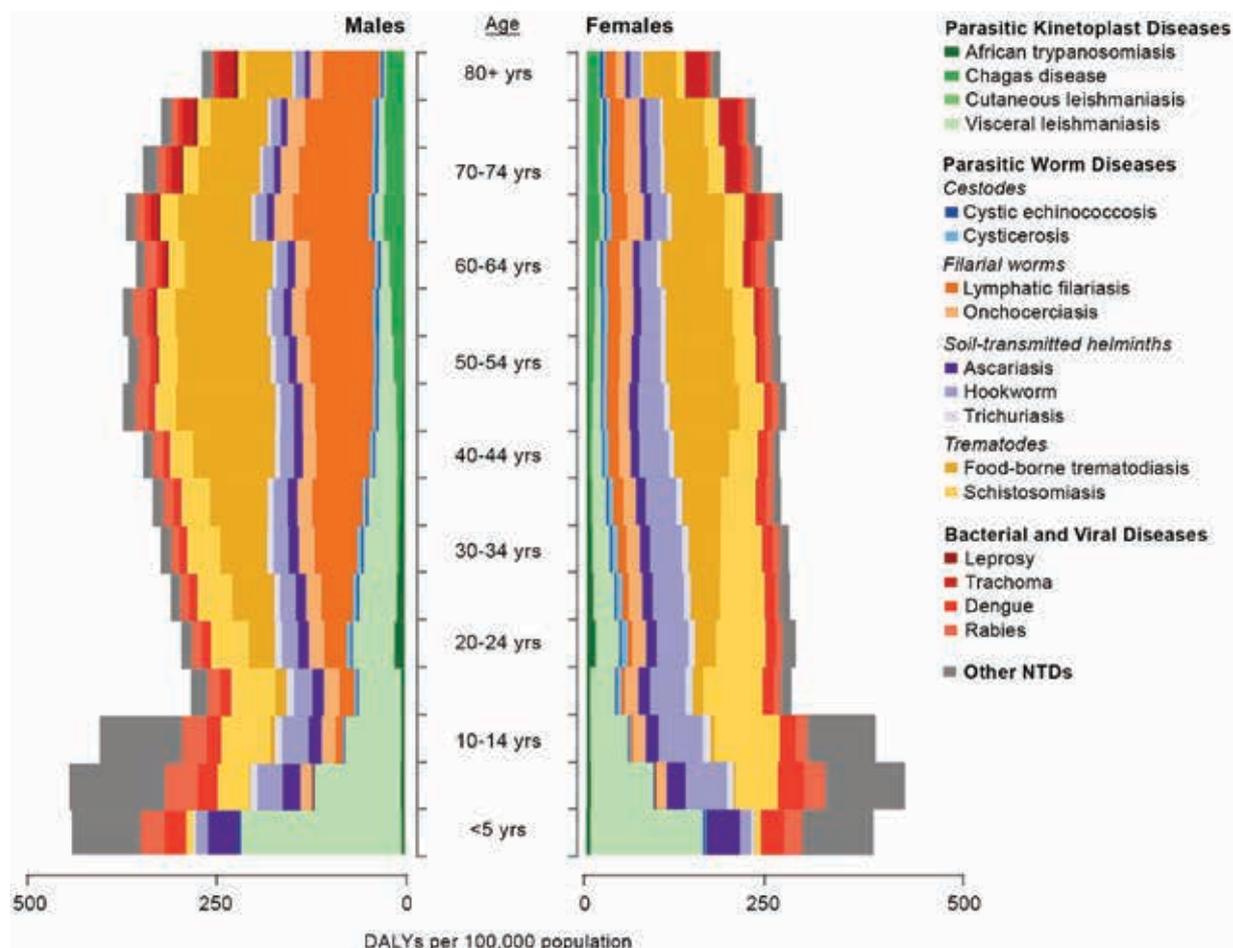
Disease	Global prevalence (in millions) in 2013	Highest regional prevalence	DALYs* (in millions) in 2013
<i>schistosomiasis and foodborne trematodiasis</i>	370.8	Sub-Saharan Africa and Southeast Asia, East Asia and Oceania	6.69
<i>lymphatic filariasis</i>	43.9	Sub-Saharan Africa	2.02
<i>onchocerciasis</i>	17.0	Sub-Saharan Africa	1.18
<i>soil-transmitted helminths</i>	1,753.6	Sub-Saharan Africa and Southeast Asia, East Asia and Oceania	2.18 (hookworm only)
<i>trachoma</i>	2.4	Sub-Saharan Africa	0.17
<i>leprosy</i>	0.7	Sub-Saharan Africa and Southeast Asia, East Asia and Oceania	0.04
<i>human African trypanosomiasis</i>	0.02	Sub-Saharan Africa	0.39
<i>leishmaniasis</i>	4.0	Sub-Saharan Africa	4.28
<i>Chagas Disease</i>	9.4	Latin America and the Caribbean	0.34
<b>Total cases (not all NTDs listed here)</b>	2,322		25.17

Source: Herricks et al. (2017).<sup>[41]</sup>

\* Disability-adjusted life years (DALYs) resulting from the NTDs.<sup>[40]</sup>

The Global Burden of Disease Study also highlighted differences in disability-adjusted life years by age and male or female sex (Figure 1). For example, for older school-aged children and adolescents, soil-transmitted helminths infections and schistosomiasis are the leading causes of disability-adjusted life years. Among adults, foodborne trematodiasis, lymphatic filariasis (especially in males) and hookworm infection are among the highest NTD burdens. Among adolescent and adult women, schistosomiasis and hookworm infection are leading causes of disability-adjusted life years.<sup>[40]</sup>

**Figure 1: Disability-adjusted life years (DALYs) per 100,000 population by age and gender in 2013**



While Figure 1 indicates that men have a greater burden of NTDs, the longer-term impact on women may be more severe because of gender inequities and a lack of power, particularly in low resource settings. Women and trans people with low socioeconomic status in lower middle income countries often experience disproportionate poverty, have limited access to education and reduced health literacy, minimal land ownership and political voice, all of which act as barriers to accessing healthcare interventions including prevention, treatment and diagnosis services, potentially increasing their exposure to and intensity of NTDs and resultant disabilities.<sup>[13]</sup> Trachoma infection in children under five years from rural communities can be as high as 60–90 percent and as women are the primary care giver, they are four times more likely than men to be permanently blinded by the disease due to the frequency of infection.<sup>[41, 42]</sup>

NTD research relating to sex and gender is limited but where it has taken place it has mainly focused on issues affecting women, with less understanding of the wider impacts on men or transgender or intersex people.<sup>[31]</sup> Yet in many communities prevailing social norms mean men are much slower to seek health care than women.<sup>[25, 43, 44]</sup>

The case study below aims to highlight the complex interplay between gender-specific variations in social context and sex-specific variations in biology and their impact on both risk of exposure and the ability of different individuals to access care and treatment. The detailed analysis of differences in health outcomes for men and women related to urogenital schistosomiasis is an illustrative example to demonstrate how a gender analysis can be undertaken to inform policy and programmes.

## CASE STUDY OF UROGENITAL SCHISTOSOMIASIS

Schistosomiasis, also termed bilharzia, is a parasitic infection caused by the schistosoma blood fluke which is transmitted via intermediate snails in vegetation of slow-flowing waters. It enters the human body through the skin during occupational activities, household tasks or play.<sup>[45]</sup> Several types of schistosomiasis are associated with infection by *Schistosoma haematobium*, *Schistosoma mansoni* and the other types of schistosomes. This case study explores urogenital schistosomiasis – which includes *S. haematobium*, urinary schistosomiasis, FGS and male genital schistosomiasis (MGS) – to show how sex and gender differentials have an impact on exposure, transmission, manifestation and treatment.

**MGS** is a manifestation of *Schistosoma haematobium* infection in boys and men which presents in the genitalia and has implications for reproductive and sexual health and long term risks of bladder cancer.<sup>[46]</sup> It also results in sperm degradation and reduced seminal fluid which can decrease fertility.<sup>[46, 47]</sup> Men have increased risk of MGS during occupational and leisure activities associated with contaminated water contact.<sup>[48]</sup> Problems with diagnosis include misdiagnosis and false negatives which can present additional risks, such as unnecessary operations and delayed treatment.<sup>[46, 49]</sup> Practices to increase the sensitivity of diagnostic testing are labour- and time-intensive which adds barriers to diagnosis in resource-restricted contexts that often have challenging terrains.<sup>[48, 49]</sup> The WHO-approved standard to treat **schistosomiasis** is a single dose of 40 mg/kg of **praziquantel**, often administered through MDA at the community level.<sup>[49]</sup>

**FGS** is a manifestation of *Schistosoma haematobium* infection in girls and women that mostly occurs during household tasks, such as cleaning, washing and cooking.<sup>[50, 51]</sup> FGS can cause infertility, menstrual and pregnancy complications, genital lesions, pain and bleeding from intercourse, anaemia, genital itching and pelvic pain.<sup>[29, 30]</sup> The typical genital changes, such as sandy patches and pathological blood vessels, can make women more susceptible to infection, such as HIV, decrease fertility and increase risk of miscarriage.<sup>[30]</sup> The mental health effects of these symptoms are still not understood and research is required to understand how to support women and other patients holistically.<sup>[39, 52]</sup> FGS diagnostics include urine microscopy, physical examination or biopsy of genital tissue, all of which have challenges. Biopsies are expensive and physical examinations are often not included in training manuals at the primary health care level.<sup>[49, 53]</sup>

Women and girls tend to only approach health services for FGS when it causes infertility or evidence of a sexually transmitted infection, at which point clinicians are unable to accurately diagnose due to a lack of training and understanding of the disease leading to sizable underestimation of FGS.<sup>[49, 53]</sup> Also, the stigma from the association of FGS with promiscuity prevents health seeking behaviour (and diagnosis) among women and girls<sup>[54]</sup> and reluctance to have gynecological investigations the first few years after sexual debut.<sup>[45, 55]</sup> Women who experience symptoms, such as lower abdominal pain or bleeding after intercourse, are reluctant to seek treatment because of stigma and the fear of being associated with having a STI.<sup>[54, 56]</sup>



**Table 2: Urogenital schistosomiasis: The interplay between sex-specific variations, gender and social determinants**

Sex-specific variations	
Female	Male
<p>Manifests in the reproductive system and genitalia, causing menstrual disturbances, pregnancy and childbirth complications, anaemia, infertility, increased risk of sexually transmitted infections and HIV and contributes to high maternal morbidity and mortality rates.<sup>[30,31]</sup></p> <p>Young girls who are not treated can experience stunting and late pubertal development from hormonal disturbances, potentially decreasing fertility.<sup>[46]</sup></p> <p>Filtered urine does not predict genital morbidity; lesions often continue after the eggs have died meaning clinical manifestations can be undetected after treatment.<sup>[49]</sup></p> <p>Diagnosis is by visual inspection of characteristic lesions on the cervix and vaginal wall and a biopsy of genital tissue. Diagnosis is difficult, requiring highly trained physicians and expensive equipment.<sup>[49, 53]</sup></p> <p>Biological changes during pregnancy mean women are restricted or excluded from praziquantel prevention and treatment interventions.<sup>[20]</sup></p> <p>Women who miss treatment due to pregnancy and breastfeeding are likely to repeatedly miss treatment and may be more susceptible to organ damage and cancer due to chronic schistosomiasis infection.<sup>[31]</sup></p> <p>Lesions caused by FGS are a risk factor for HIV acquisition and co-infection.<sup>[111]</sup></p>	<p>Manifests within the genitalia and affects the skin, spermatic cord, testes and prostate leading to enlargement of the organs and pain during urination.<sup>[46]</sup></p> <p>Can cause weak erections, rapid ejaculation, diminished libido, infertility and bladder cancer.<sup>[115]</sup></p> <p>Manifestations can be incorrectly diagnosed as cancer resulting in surgeries that alter the reproductive capacity and delay effective treatment.<sup>[46]</sup></p> <p>Diagnosis by microscopy of filtered urine lacks sensitivity, especially for detection of light infections, leading to a strong bias toward false negatives.<sup>[49]</sup></p> <p>Treatment using single dose of praziquantel.<sup>[49]</sup> MGS can cause higher HIV viral loads increasing HIV transmission to women.<sup>[20]</sup></p>
Gender, social and environmental determinants	
Women	Men
<p>Increased risks associated with environmental factors of contact with contaminated water through household roles of collecting water, washing and cleaning.<sup>[50, 51, 54]</sup></p> <p>Women and girls accessing treatment for vaginal symptoms are often highly stigmatized and referred to sexually transmitted infection clinics as opposed to receiving treatment.<sup>[45, 55]</sup></p> <p>In some contexts, religious and cultural norms can mean women's bodies are more covered or they have restricted water-related activities, such as swimming and bathing, reducing risk of schistosomiasis.<sup>[27]</sup></p> <p>Girls not attending school because of caring responsibilities in the home or cultural preferences to educate boys miss out on preventive treatment and have increased risk.<sup>[39]</sup></p>	<p>Increased risks associated with occupations such as fishing and swimming that involves contact with contaminated water.<sup>[116]</sup></p> <p>Older men in some contexts will not receive preventive treatment from younger women distributors.<sup>[81]</sup></p> <p>Efforts to protect a masculine image and fears of economic implications of a diagnosis can prevent men from seeking health care early.<sup>[25]</sup></p>

Where one case of FGS is found it is likely there are others as peers will be using the same water source. Understanding this could ease processes of identification and test and treat strategies.<sup>[53]</sup> Treatment using praziquantel kills the adult worms, prevents the development of new lesions, and can improve reproductive health and diminishes some FGS symptoms. The regular treatment of young girls in communities and schools is important to prevent FGS.<sup>[53, 54]</sup> Teachers have a role to play in educating children about prevention practices and potential symptoms<sup>[50]</sup> using age-appropriate tools and games such as 'Schisto and Ladders' developed in Nigeria.<sup>[57, 58]</sup> In some settings, poverty and cultural practices restrict girls' school attendance; additional mechanisms are required to reach out-of-school children for prevention.

Treatment should be accompanied by tackling environmental risk factors. The amount of contact women and girls have with snail infested waters, especially in rural areas, is a major cause of FGS.<sup>[52, 55]</sup> In South Africa, high coverage of piped water in the community decreased a child's risk of urogenital schistosomiasis infection eight-fold.<sup>[51]</sup> This demonstrates the importance of providing safe water and that levels of urogenital schistosomiasis infection could be reduced to low levels in rural African settings by delivering clean water to homes.<sup>[51]</sup> Continued advocacy and pooling of resources with other waterborne disease programmes could advance the water agenda.

To tackle FGS and MGS, responses must be integrated into the public health system with a multi-sectoral response that engages directors of Public Health, Family Health (Reproductive Health), Education and Water and Sanitation.<sup>[39]</sup> Advocacy should ensure that relevant health staff such as clinicians, public health officers, obstetricians and gynecology consultants, nurses and community health workers are informed and able to identify and treat FGS.<sup>[39]</sup> Health workers require training for FGS and MGS at the national, regional, district and community levels including in-service and refresher training to increase context-sensitive diagnosis and treatment.<sup>[39]</sup>

## **CHANGING CONTEXTS MATTER**

How and where NTDs affect people of all genders is situated within a broader political and environmental context that includes issues such as inequality, political instability and violence, displacement, urbanization and migration.<sup>[59, 60]</sup> For example, urogenital schistosomiasis was historically associated with rural areas, however, it is establishing itself within urban populations, possibly due to increases in migration, commuting spouses and roadside rural and peri-urban communities.<sup>[61]</sup> Political instability and lack of resources limits the capacity of governments to manage environments, control disease transmission and ensure an effective health system.<sup>[59]</sup> For example, in 2016 the impact of the war in Yemen restricted field campaigns from identifying cases of leishmaniasis and prevents leishmaniasis patients from reaching treatment centers.<sup>[62]</sup> The war also created migration of city inhabitants to villages, where leishmaniasis is endemic, thus increasing the numbers of cases among people who were considered urban inhabitants before the war. Wounds in injured fighters provide easy access for leishmaniasis vectors. Women, with men no longer present at home, adapt to making decisions about seeking health care independently.<sup>[62]</sup>

Human and environmental ecology impact where and how people of all genders become infected with NTDs.<sup>[63]</sup> For example, several insect vectors are likely to better reproduce and transmit diseases within certain ranges of temperature and humidity that may be geographically specific.<sup>[64]</sup> The distribution of social roles by gender, results in differential risks as they interact in different ways with high-risk areas for work, play and household tasks.<sup>[64]</sup> Families and communities that engage in outdoor activity for labour and income, such as agricultural or sustenance farming, are more likely to encounter NTDs than those in other professions.<sup>[64, 65]</sup> For example, schistosomiasis prevalence in Itapinassu, Brazil, was positively associated with increasing age, male sex, residence in the village for more than five years, daily water contact, fishing, laundering, less than a 10 metre distance from an infected stream, lack of cesspools and chronic undernutrition.<sup>[65]</sup> People responsible for collecting water and children who play in water or mud may be exposed to NTD vectors that thrive near aquatic environments. Poor sanitation due to inadequate garbage disposal/collection and cracked walls and damp earth floors can also result in breeding sites for many NTD vectors (such as the sand fly which carries leishmaniasis) and subsequently increased risk, especially for those living in poverty.<sup>[63]</sup> As people make changes to the environment or relocate for economic or political reasons, alterations in the range and densities of the vectors and reservoirs can increase exposure to risk.<sup>[66]</sup>

Furthermore, climate change, such as increased temperature and changes in precipitation patterns, may facilitate the migration of NTD vectors into new regions where they previously were not endemic and create changes in agricultural practices and migration.<sup>[67]</sup> Increases or decreases in water bodies can lead to changes in disease vectors and behaviour of people, as people may have to venture further for water and work, potentially creating new risks of NTD infection.<sup>[68]</sup> It is important that biological differences between males, females and intersex people and the ways in which sex and gender shape vulnerability within different environments are recognized and considered by NTD programmes so they can identify and respond to differing needs associated with prevention, diagnosis and treatment.<sup>[22]</sup>

Another consideration is urbanization which can increase the incidence and prevalence of NTDs.<sup>[63]</sup> In Kampala, a survey of 915 adults found that urban farmers had an increased risk of soil-transmitted helminths and schistosomiasis through their living and working conditions which involved contact with infected wastewater and fecal sludge.<sup>[69]</sup> Although women were also farmers, men were more likely than women to work in managing fecal sludge and maintaining drainage channels and sewage treatment, thus further increasing their risk.<sup>[69]</sup>

Considering context is important in the design and implementation of NTD control programmes, particularly those reliant on community directed treatment strategies.<sup>[70]</sup> In Ghana, MDA coverage in the Greater Accra region is only 71 percent, compared to an average of 82 percent in surrounding regions.<sup>[71]</sup> This programme relies on community structures present in rural areas whereas Greater Accra is more urban and, as with many urban settings, has a mixed population with varying social, cultural and gender norms. Urbanization presents less resilient and more diverse community structures which bring challenges for MDA implementation. Implementation research is needed to explore how existing strategies can be adapted to address new, complex and changing contexts.<sup>[70]</sup>



## SECTION 2: RECOMMENDATIONS FOR ADDRESSING NEGLECTED TROPICAL DISEASE-RELATED GENDER INEQUITIES

Public health programmes to detect and enhance control, prevention, elimination and eradication of NTDs are being implemented in over 74 countries worldwide.<sup>[3, 4]</sup> These programmes are supported by national and global health and developmental organizations as well as partners from donor agencies and the biomedical industry.<sup>[1, 4]</sup> The total NTD investment target for the period 2015–2030 is \$34 billion, excluding medicines.<sup>[3]</sup> To scale up interventions to achieve control, elimination or eradication of NTDs, programmes must be integrated into the health systems of endemic countries.<sup>[72]</sup> NTD responses require national and international harmonization with coordination of partnership activities that directly (or indirectly) impact NTD control.<sup>[72]</sup> Explicit attention to the gender dimensions of NTDs and how they intersect with other social determinants can ensure programmes and interventions are equitable, more effective and do not harm efforts to achieve gender equality.

Governments and civil society organizations are beginning to understand the importance of gender mainstreaming in NTD programmes, but an intersectoral gendered approach is required that is owned institutionally, funded adequately and implemented effectively.<sup>[73]</sup> To further this process, WHO has produced a toolkit for NTD programme managers at national and subnational levels and other partners to build in-country capacity to collect and analyse existing and additional quantitative and qualitative data.<sup>[74]</sup> This will help to identify the differences in access to and impact of preventive chemotherapy according to sex, age, occupation, residence, income and other social factors, as well as identify facilitators for coverage and barriers driving inequities.<sup>[74]</sup> By understanding these differences an action plan can be developed that takes a whole of society approach that engages civil society, patients' rights advocacy groups, communities, the private sector, United Nations entities and donors.

At the same time, by examining how gender and society interact to shape who is infected with NTDs, who accesses preventive medicines, who is diagnosed and treated or not, who is exposed or vulnerable to NTDs and how and whose behaviour is risk prone or risk-averse, inequities can be challenged and addressed. The gender framework proposed by Morgan and colleagues (2016) (Appendix 1) can be a useful tool to assess how the division of labour, bargaining power, access to resources, social norms, ideologies and beliefs of different genders affect exposure, risk of transmission, prevention and treatment of NTDs.<sup>[75]</sup> This framework is situated around health and health systems development, is holistic and can help researchers, policymakers and practitioners understand and address the sex and gender power relations most relevant to NTD programmes.

Guided by this framework, recommendations have been identified that explicitly account for sex and gender in the design and roll-out of programmes. In specific, the recommendations call for examining how sex and gender relates to: a) NTD risk and prevention; b) accessibility and acceptability of treatment; and c) stigma and mental health. Greater investment in sex-disaggregated data and implementation research on sex and gender and NTDs is equally essential.

### **RECOMMENDATION 1: ACCOUNT FOR HOW SEX- AND GENDER-RELATED DIVISIONS OF LABOUR, EVERYDAY PRACTICES, SOCIAL NORMS AND BELIEFS WITHIN AND BEYOND THE HOUSEHOLD IMPACT NEGLECTED TROPICAL DISEASE RISK**

Understanding labour roles and everyday practices of people of different sexes and genders in relation to demographics and social determinants – and their impact on NTD disease burden – is important. Gender roles and practices need to be considered when designing effective health promotion campaigns, selecting protective factors, such as bed nets and vector control mechanisms, and identifying hot spots for NTDs.<sup>[76, 77]</sup> That is because the division of labour within and beyond the household and everyday practices

intersect with other determinants, such as age and socio-economic status, to affect exposure to NTD risks.<sup>[74]</sup> For example, in contexts in which fishing, farming or hunting are the main income activities, prevalence of lymphatic filariasis in men is higher, especially where men sleep outside during these activities.<sup>[78]</sup> On return to the community, however, men also increase the risk of lymphatic filariasis infection for other community members.<sup>[78]</sup> However, where people have similar occupational activities, such as agricultural work as found in rural India, lymphatic filariasis infection patterns among men and women are almost equal.<sup>[77]</sup> Likewise, in some contexts, religious and cultural norms can mean women's bodies are more covered or women have restricted water-related activities, such as swimming and bathing, reducing the risk of waterborne diseases.<sup>[27]</sup>

Research studies from different contexts, as described below, demonstrate the complex interaction between sex and gender and other factors.

- In a rural province of Kenya, focus group discussions with 237 adults found that both boys and girls spent most of their time playing in water, but as they got older, playing time reduced. However, many girls continued to spend more time in water than boys of the same age, washing dishes and clothes in water infested with the vector snail resulting in higher rates of schistosomiasis for females.<sup>[44, 54, 55]</sup>
- In Yemen, it is mostly boys and women who work in agriculture, care for animals and are responsible for procuring water, especially at dusk and in the early morning, which increases their exposure to sand fly bites and their risk of leishmaniasis.<sup>[62]</sup>
- In many contexts, children and men prefer playing and working with exposed bodies, such as in rural Cameroon, making them more prone to bites from black flies and consequently increasing their risk of onchocerciasis, whereas women tend to be more covered offering some protection.<sup>[79, 80]</sup>

Communities often have no choice but to use infected waters for washing, cooking and cleaning. Unless structural and environmental factors are addressed by investing in permanent infrastructure that enables communities to access safe water, sanitation and hygiene, many NTDs and other communicable diseases will not be eliminated, and certainly not eradicated.<sup>[8]</sup>

## **RECOMMENDATION 2: ACCOUNT FOR HOW SEX AND GENDER IMPACT THE ACCESSIBILITY AND ACCEPTABILITY OF TREATMENT**

### **2.1 PREVENTIVE CHEMOTHERAPY**

Preventive chemotherapy is aimed at optimizing the large scale use of safe, single-dose drugs to reduce the extensive morbidity associated with NTDs. MDA involves distributing drugs, often donated by biomedical companies, either through school-based treatment of children between the ages of 5–14 or through community-based treatment programmes.<sup>[31]</sup> For the latter, community drug distributors (CDDs) are selected by community members, who are then trained and supervised by the health sector to distribute the drugs to each household or from a fixed point in the community. In schools, teachers are usually responsible for drug distribution.<sup>[31]</sup>

Gender relations, occupations and other cultural and social factors affect accessibility and acceptability of these drugs.<sup>[81]</sup> Treatment registers can reflect differences in gender, however, they are not always complete, making it difficult to undertake intersectional analysis to identify who is missed.<sup>[31]</sup> Men can disproportionately be missed during MDA campaigns as they are more likely to work away from the home and have been reported to be more distrustful of treatment.<sup>[74]</sup> In eastern Uganda, a study with over 400 participants across eight villages in two districts found that women were more willing to accept and adhere to advice and information provided by the CDDs than men.<sup>[31]</sup> The context in which distributors are working will determine the advantages and challenges experienced by CDDs of different genders. In the northwest and southeast of Uganda, ethnographic observations across five districts over four years found that underlying gendered hierarchies meant that older men offered drugs by younger woman resulted in refusal to swallow them, instead putting the tablets in their pocket, whereas when a man issued the drugs, they were more likely to be accepted on the spot.<sup>[31, 81]</sup> In contrast, women CDDs were required in Nigeria, where social norms forbade a man from entering the household without another man present

(in this case a woman CDD increases access for women).<sup>[74]</sup> Studies have found that in some situations women were prohibited from seeking or taking MDA because of their husbands' negative beliefs regarding the treatment.<sup>[82]</sup> In one study, boys stated that they would be more receptive to the treatment if other adolescents were to distribute drugs and girls were influenced by their parents' decision to accept the drugs or not.<sup>[31]</sup> Other contextual factors should also be considered, for example in the Nubian Desert area of north-eastern Sudan, certain nomadic groups did not allow contact of women and girls with Sudanese health workers distributing drugs because the health workers were of a different ethnicity, thus presenting difficulties in provision and monitoring of MDA to these individuals.<sup>[7]</sup>

As seen above, the genders of CDDs matters and varies by context. This factor influences access and acceptability of MDA to individuals, households and communities. Sex and gender disaggregated data collection that also reflects the gender of the distributor will help shed light on potential gendered biases in MDA delivery. Policies and programmes should provide critical questions to help district and local implementers consider who is recruited as a CDD and where they will be best placed.<sup>[7]</sup> By providing training and supportive supervision structures, drug distributors could reflect on how they promote gender equity in their work and can consider which 'coverage improvement' strategies will be most appropriate in different contexts.<sup>[7]</sup>

Power relations and social roles allocated to genders within different contexts have an influence on how MDA programmes are implemented within communities. In some areas of Nigeria, men were often responsible for selecting CDDs who tended to select other men because of gender bias, including the common perception that women were too weak to take on the task of being a CDD.<sup>[74]</sup> This means that women were not provided the opportunity to disprove preconceived views on their aptitudes. On the other hand, when women in Afghanistan had the opportunity to undertake close-to-community provider roles, like CDDs, they reported increased mobility, knowledge and capacity to help others, which the women viewed as empowering.<sup>[83]</sup> In Iran, women health volunteers reported increased social engagement, feelings of accomplishment and respect for their role from their husbands and other community members.<sup>[84]</sup> A systematic review of drug distribution for onchocerciasis demonstrated the need for more women CDDs as women were found to be more committed, persuasive and more patient than men in the distribution of ivermectin.<sup>[85]</sup>

It remains important to ensure that inequalities are not exacerbated from women only having an opportunity to undertake volunteer roles without payment or incentives.<sup>[50]</sup> Other considerations for women as CDDs should include recognizing that women are often caregivers, which can create difficulties for women to make time to meet at a central location for distribution or to walk long distances to reach households.<sup>[82]</sup> Women from rural low income areas, in particular, already have considerable daily tasks to ensure survival and sustenance and undertaking additional roles can risk further lost economic opportunities.<sup>[86]</sup> When implementing NTD programmes, these factors should be considered so that health systems, donors and implementing partners provide adequate remuneration and support to women and other CDDs so that inequalities in gender and income are not further exacerbated.

## **2.2 GENDER-RELATED QUESTIONS FOR MASS DRUG ADMINISTRATION PROGRAMME MANAGERS TO CONSIDER**

Gender frameworks can support programme managers to ask gender-related questions within MDA approaches, such as those found in Box 4 (proposed by Theobald et al., 2017). Such frameworks are effective to start collective thinking and to develop a deeper understanding and ownership of gender determinants, ensuring that gender questions under review are adapted to context.<sup>[7]</sup>

#### **Box 4: Sample questions for mass drug administration programme managers to consider from a gender perspective**

- Who is chosen to distribute the drugs and why?
- How are they chosen and who is involved?
- Does the CDD's gender affect their ability to access certain household members or enter the home?
- Does this access also influence individual, household and community adherence?
- Who attends school? How is this linked to gender and poverty?
- What happens to those who do not attend school on a regular basis?
- What are the 'coverage improvement' strategies?
- Who decides on these strategies?
- What baseline/census material do the strategies relate to and who might be potentially excluded?
- Where appropriate, how can the strategies ensure that women and transgender people who are pregnant (and unable to take certain drugs) access the drugs at a later, more appropriate date?

### **2.3 INTENSIFIED CASE MANAGEMENT, HEALTH SEEKING, DIAGNOSIS AND HOLISTIC TREATMENT**

Social, cultural and economic differences on the basis of sex and gender can affect an individual's decision to access health care for diagnosis and case management.<sup>[8]</sup> Intensified case management for NTDs not treatable through preventive chemotherapy entails caring for infected individuals and those at risk of infection. The key success factors include making the diagnosis as early as possible, providing medical treatment to reduce infection and morbidity, managing complications and providing psycho-social support to patients and their families.<sup>[8]</sup> Treatment and management of intensified case management diseases has historically focused on the medical management of these diseases with little consideration of their social consequence. The stigma associated with these diseases coupled with their psycho-social impact must be better understood from a gender perspective to ensure that patients are not left with unmet social support needs.

Levels of autonomy, power and decision-making within a household can have an impact on who and when health care can be accessed. For example, studies have demonstrated that women with signs of NTDs often delayed seeking health care until their husband or guardian agreed thus resulting in more severe disease outcomes.<sup>[6, 87]</sup> In some contexts, like West Bengal, India, interviews with 104 women showed that they had to complete their household chores before setting out for the hospital and continued with chores after their return. Too much time spent waiting at various service points conflicted with domestic work and lowered women's social worth which de-motivated them from seeking and continuing with treatment for leprosy.<sup>[87]</sup> Treatment regimens that advised avoiding prolonged walking and standing or working with hot utensils was not practical and so not adhered to.<sup>[87]</sup>

Other reported reasons for women receiving delayed health care too late include restricted movement, low perceived need for diagnosis and treatment by a male family member, the view that women's health care is not as important as that of male family members, women's lack of financial decision-making authority to pay for services and fears of how the condition may affect their status in the family.<sup>[88]</sup> In India, there is a perception that lymphatic filariasis is hereditary in women and is therefore not recognized as a condition that can be treated clinically, causing a delay in presentation at health facilities.<sup>[89]</sup> When women do present at health services, health workers may not believe women's experience of symptoms, so these women question themselves.<sup>[94]</sup> To address inequities found within intensified case management of NTDs, education of health workers is necessary to provide accurate information through better communication techniques, while considering a women's perception of illness. This has the potential to empower women

to be more actively involved in disease prevention.<sup>[90]</sup> In addition, increasing the numbers of women health workers and volunteers may improve the experiences faced by female NTD patients.

For men, hegemonic masculinity and prevailing gendered norms which combine sexual functioning and social responsibilities can present barriers to accessing diagnosis and treatment. In an ethnographic study of over 100 men with hydrocele in Kassena-Nankana District, Ghana, a 'real man' was described as someone who can satisfy a woman sexually, has many wives and children, large farms and the ability to provide for the total needs of the family.<sup>[25]</sup> To protect their 'manliness,' men with hydrocele delayed seeking formal health care and instead chose to access 'drug peddlers' to manage pain.<sup>[25]</sup> Fear of the cost of surgery or death further prevented men from seeking care. One man described this well, asking "I know I have to go in for an operation, but what if I die? Who will take care of my children and my family?"<sup>[25]</sup> National programmes that emphasize culturally-acceptable health education and promote early reporting of signs of disease could lead to earlier use of health services.<sup>[87]</sup>

## **RECOMMENDATION 3: ADDRESS SEX- AND GENDER-RELATED STIGMA AND MENTAL HEALTH IMPACTS OF NEGLECTED TROPICAL DISEASES**

Understanding sex- and gender-related stigma as a consequence of NTDs will help to minimize the negative impact of associated stigma, reduce discrimination, support social acceptance, improve disease control and knowledge and prevent disability.<sup>[91]</sup> Social isolation is common among people living with NTD-related illness and disability. Stigma also damages marriage prospects.<sup>[92]</sup> Women living with onchocerciasis, leprosy and lymphatic filariasis describe feelings of embarrassment, shame, sadness, despair and fear.<sup>[19, 87, 93]</sup> Studies indicate that women leprosy patients are more severely affected by stigma than male patients.<sup>[91, 94]</sup> This phenomenon is thought to be due to male dominance in patriarchal societies, socioeconomic dependency on men as primary income providers, gender-based violence and constant responsibility for the care of others.<sup>[91, 94]</sup> Women stigmatized due to skin diseases are often already experiencing poverty and poor nutrition, and the progressing disease means a future of psychological distress complicated by aging that can reduce their ability to cope with adverse circumstances.<sup>[95]</sup>

Research studies in different contexts below demonstrate the complex interactions between gender and stigma.

- A qualitative study in Tanzania with 58 participants including men, women and health facility staff found that young girls refused to undergo gynecological screening for fear they will be tested for sexually transmitted infections or that the process will disrupt their reproductive capacity.<sup>[56]</sup> In Nigeria, however, a small study identified that boys associated blood in the urine from schistosomiasis as a sign of adulthood but did not face the same stigmatization.<sup>[56]</sup>
- In Mali, one study of 58 women who were infertile reported marital tensions, criticism from relatives and stigmatization from the community. The women reported sadness, loneliness and social deprivation.<sup>[96]</sup>
- Men with hydrocele in Uganda reported ridicule from community members for having lymph scrotum and reported being shunned, receiving insults and there was an association of the disease with being unclean.<sup>[25]</sup>

Currently, a lack of service provision addressing the stigma related to severe skin diseases results in significant physical and psycho-social consequences for all affected. Physical impairment worsens because of delayed diagnosis allowing disease progression. Alternative treatment may be sought from sources outside the health system, often with catastrophic economic and social consequences for patients and households.<sup>[97]</sup> Integrated health system approaches to the management of NTDs that address stigma have been suggested as a solution to these problems, however, more evidence that evaluates the feasibility of approaches that tackle stigma from patient, community and health system perspectives is required.<sup>[97, 98]</sup> For example, an integrated lymphedema management programme in India found positive impacts were emphasized by patients and that many family and community members indicated more acceptance and understanding of the cause of the disease within the community.<sup>[99]</sup> Gender analysis is critical when considering co-morbidities between mental health and NTDs. Constructions of mental health often vary

significantly between genders.<sup>[100]</sup> Litt et al. (2012) recommend that mainstreaming NTDs within mental health services is essential to meet patients' psycho-social support needs.

Management of mental health and psychological stress caused by gender-related stigma as a consequence of NTDs should be integrated within wider health systems and services.<sup>[95]</sup> Creating awareness of social stigma among health professionals and communities is necessary to reduce patient suffering, change health-seeking behaviour and promote treatment adherence; awareness also affects political commitment for disease control.<sup>[101]</sup> Since women and girls are more affected by NTD-related stigma, additional support needs to be provided for women and girls to manage short and long-term consequences related to social issues such as marital position and economic status.

## **RECOMMENDATION 4: COLLECT AND USE SEX- AND GENDER-DISAGGREGATED DATA AND IMPLEMENTATION RESEARCH TO CONTINUOUSLY IMPROVE NEGLECTED TROPICAL DISEASE PROGRAMMING AND ENSURE EQUITY**

Collecting and using sex- and gender-disaggregated data to improve the gender equity and responsiveness of NTD programmes, especially at district and community levels, is important. Gaps in disaggregated data at the district and community, national and global levels can be addressed by adding gender equity questions to coverage evaluation surveys and data quality assessments.<sup>[74]</sup> WHO introduced sex-disaggregated reporting forms in 2009, however, the way in which this disaggregated data is reported, collected and used is not always clear.<sup>[7]</sup> Sex-disaggregated data analysis can hide gender differences at the community level, for example misreported prevalence rates that are more related to how and when women, men and trans people come into contact with the health system can mean some populations remain missing from treatment efforts. Sex- and gender-disaggregated data is often collected for binary, mutually-exclusive categories only, leaving out important insights about the health of transgender and intersex people. Better training and supportive supervision for data collectors around household access and inclusion could help minimize this effect.

In eastern Uganda, quantitative data on the number of persons treated by age and gender was identified from treatment registers in each village, together with qualitative data collected through semi-structured interviews with sub-county supervisors, participant observation and focus group discussions. Participants included community leaders, CDDs, men, women who were pregnant or breastfeeding at the time of mass treatment and adolescent males and females.<sup>[31]</sup> Even though treatment registers were often incomplete, analyzing available quantitative data alongside additional insights from qualitative findings provided initial equity information for action and a data foundation on which to build.

Funding for monitoring and evaluation tends to be limited as resources are directed towards intervention delivery. This impedes the data collection required to determine whether modifications to programmatic activities are needed to increase programme equity.<sup>[102]</sup> High levels of data aggregation also limit the ability for true intersectional analysis at lower levels of the health system as it becomes impossible to cross analyse at the individual and community level.

To act on gender-specific dimensions of NTDs, it is necessary to invest resources towards supporting implementation research which facilitates health systems, partners and researchers to work together to identify and to address the gaps in understanding. Implementation research could inform how NTD programmes can solidify gender equity as an underlying principle in policy development, advocacy, legislation, resource allocation, planning, implementation and monitoring. This would help ensure that NTD programmes meet the needs of both women and men and consider the experiences and needs of people of other genders. Research is recommended to understand how to support frontline health workers, teachers and CDDs to enhance their critical awareness of gender norms and power dynamics within communities and how they can impact accessibility and acceptability.<sup>[7]</sup>

More research funding to examine the links between biomedical and social determinants of health with a focus on gender and intersectionality should be made available. In particular, it is critical to instigate key indicators or milestones that are disaggregated by gender and other social stratifiers such as age and wealth in carrying out such a research.<sup>[73]</sup>

## **RECOMMENDATION 5: TAKE A HEALTH SYSTEMS APPROACH THAT PROMOTES INTERSECTORAL PROCESSES AND PUTS COMMUNITY ENGAGEMENT AT THE CENTRE OF NEGLECTED TROPICAL DISEASE PROGRAMMES**

NTD programmes benefit from a health systems approach that identifies positive synergies between disease-specific interventions, non-targeted health services and other sectors.<sup>[103]</sup> This is particularly true for gender and NTDs for which a multisectoral approach is required to mainstream gender-specific actions that have the potential to equitably reduce NTDs and their impact on families. A good example of promoting multi-sectoral approaches at the same time as strengthening health systems can be found in the Guinea worm eradication campaign.<sup>[104]</sup> The strategy addressed water supplies, health education, case management and vector control and embedded actions that recognized gender- and age-associated risk factors. The advocacy effort brought together a range of donor agencies who supported a mix of water supply programmes, technical assistance, vehicles, filter cloth, temephos (a larvicide), staff and volunteer training and field allowances; this was combined with commitments from government bodies. A series of regional conferences and meetings, including programme review meetings, brought together national programme coordinators who gave presentations on country programmes, which helped sustain the development of joint planning and performance indicators.

Intersectoral efforts, such as the Guinea worm eradication campaign, that include the development of shared indicators and objectives can foster the expansion of effective integration programmes that work together to promote gender equality and equity in health.<sup>[105]</sup> NTD partners, policymakers and planners should utilize such examples to identify gaps and then to create potential synergies that can tackle gender inequities created by structural factors like environment, infrastructure, education and funding restraints. WHO is promoting a new global strategy called 'Water, sanitation and hygiene for accelerating and sustaining progress on NTDs.'<sup>[106]</sup> Nigeria has created a national NTD steering committee with a number of sub-committees, one of which is 'NTDs and Water, Sanitation and Hygiene.'<sup>[107]</sup> Each sub-committee holds side meetings, reporting back to the plenary on current initiatives and proposed NTD programme focus areas relevant to their thematic area.<sup>[107]</sup> When gender-related goals are introduced at sub-committee level, it paves the way for gender inclusion in planning across all sectors.

At the very centre of NTD control and elimination programmes should be a strong community voice so that no sections of the population are 'left behind.' Health systems need to support community participation mechanisms that not only engage people of all genders at risk or living with NTDs, including women and girls, but that also ensure their views inform future NTD programme development and implementation. Civil society can help ensure effectiveness and community accountability that addresses gender differences and other social determinants in NTD programme design and implementation. CDDs and other community health workers have local knowledge and the ability to come up with realistic solutions for NTD control and elimination problems;<sup>[108]</sup> their inclusion could help eliminate inequitable programme delivery if they are regularly consulted about gendered risk factors and health seeking behaviours.

Strengthening health systems through NTD programmes has the potential to increase the capacity of health systems year after year. The Guinea worm campaign improved surveillance systems, not only for Guinea worm but also for other diseases and the training of volunteer community health workers who were then integrated into the health system continued to be part of the primary health care system. In southern Sudan, the programme's training and supervision system was used for a pilot programme in which health volunteers in remote villages were trained to identify and treat fever and malaria, cough and difficult breathing and dehydration due to diarrhoea. Health systems strengthening in the form of co-implementation with other disease programmes (HIV, malaria, tuberculosis) as well as integration into other routine primary health service points, such as those focused on mental health, outpatient services and clinics, has great potential to maximize outcomes.

### **Box 5: Neglected Tropical Diseases and HIV/AIDS co-infection**

The relationship between HIV/AIDS and NTDs has been explored since the 1990s.<sup>[109]</sup> For lymphatic filariasis, human African trypanosomiasis and onchocerciasis, no evidence of a direct interaction with HIV exists. However, the occurrence of these parasites as opportunistic infection agents has been reported in the presence of HIV infection due to interactions with the immune system.<sup>[59]</sup> People living with HIV who also have a comorbidity with onchocerciasis can exhibit significantly reduced antibody response.<sup>[109, 110]</sup>

Evidence shows high geographic overlap between soil-transmitted helminths and schistosomiasis and HIV, exhibiting co-infection across 43 sub-Saharan African countries.<sup>[36, 61, 111]</sup> Urogenital schistosomiasis is now a recognized co-factor in HIV transmission for men and women due to local genital tract and global immunological effects.<sup>[111]</sup> It is unclear if this is also the case for intersex people with genital variations. The high prevalence of soil-transmitted helminths and schistosomiasis can increase risk factors for HIV infection and can have a worse impact on the clinical course and progression of HIV. MGS increases the risk of HIV transmission to women through higher HIV viral loads in seminal ejaculation<sup>[20]</sup> and inflammatory alterations.<sup>[111]</sup> Furthermore, schistosomal co-infection may accelerate HIV disease progression.<sup>[111]</sup>

FGS, in particular, increases the risk of HIV because the lesions provide easier access to deeper vaginal cell layers during intercourse with an infected partner.<sup>[111]</sup> The presence of lesions in childhood makes it likely that urogenital schistosomiasis is a risk factor for HIV acquisition rather than the other way around. This raises the importance of ensuring that prevention using praziquantel through school-based distribution is scaled up in endemic areas to reduce HIV infection.<sup>[111]</sup> However, as girls are less likely to attend school, additional methods of distribution are required to prevent girls and young women from an increased risk of both FGS and HIV.<sup>[39]</sup> Young adolescents generally are most at risk of contracting HIV but are often missed during praziquantel MDA programmes.<sup>[46]</sup>

For women, girls and trans people, clinical, randomized and epidemiological studies are needed for the development of field diagnostic tools, and future mass treatment programmes should include adult women and trans people to reduce morbidity and prevent HIV.<sup>[46]</sup> Point-of-care colposcopy operated by midwives could become a feasible integration strategy in ongoing cervical cancer clinics across sub-Saharan Africa for the diagnosis of FGS.<sup>[112]</sup> Integrated approaches to addressing FGS alongside other women's health issues by embedding services into the health system and moving away from traditional vertical programming for NTDs are needed. If not, FGS will remain a neglected gynecological disease.<sup>[46, 52]</sup> Joint actions need to be developed so that maternal, sexual and reproductive health and HIV services prevent, diagnose and treat FGS.<sup>[39]</sup>

Hotez et al. (2009) estimates that 120,000 new cases of HIV could be averted through regular praziquantel treatments in the next decade.<sup>[113]</sup> Even though links between HIV and schistosomiasis have been established, there is still a large gap in epidemiological assessment and a significant underestimation of the burden of FGS.<sup>[36, 52]</sup> It is equally important to treat MGS as part of HIV prevention. In addition, more research is needed to understand whether MGS symptoms are reversible after praziquantel treatment and the impact that can have on HIV prevention.<sup>[46]</sup> Advocacy exists for NTD control programmes to scale-up mass treatment interventions in areas with high prevalence rates of NTDs and HIV, to both decrease susceptibility to HIV infection and improve morbidity levels in people with co-infections.<sup>[109]</sup>

# CONCLUSION

This discussion paper has explored how social factors such as poverty, age and stigma intersect with sex and gender to create and exacerbate inequities. It has stressed the importance of considering and acting upon gender dimensions that influence risk of transmission, experiences of symptoms and access to interventions and health care. Gender inequality and inequity in relation to NTDs is predominantly socially governed and therefore actionable. Gender norms, beliefs, roles, access to resources and decision-making constitute gender power relations.<sup>[6, 75]</sup> These relations intersect with other social determinants of health, such as age, socio-economic status and structural and environmental dimensions of daily life that govern how power is embedded within social hierarchies.<sup>[73]</sup> However, the ways in which gender roles and relations shape vulnerability to NTDs, access to prevention and treatment and experience of living with NTDs is too often ignored and the underlying social injustices need to be challenged in order to contribute to the achievement of multiple SDGs.<sup>[114]</sup>

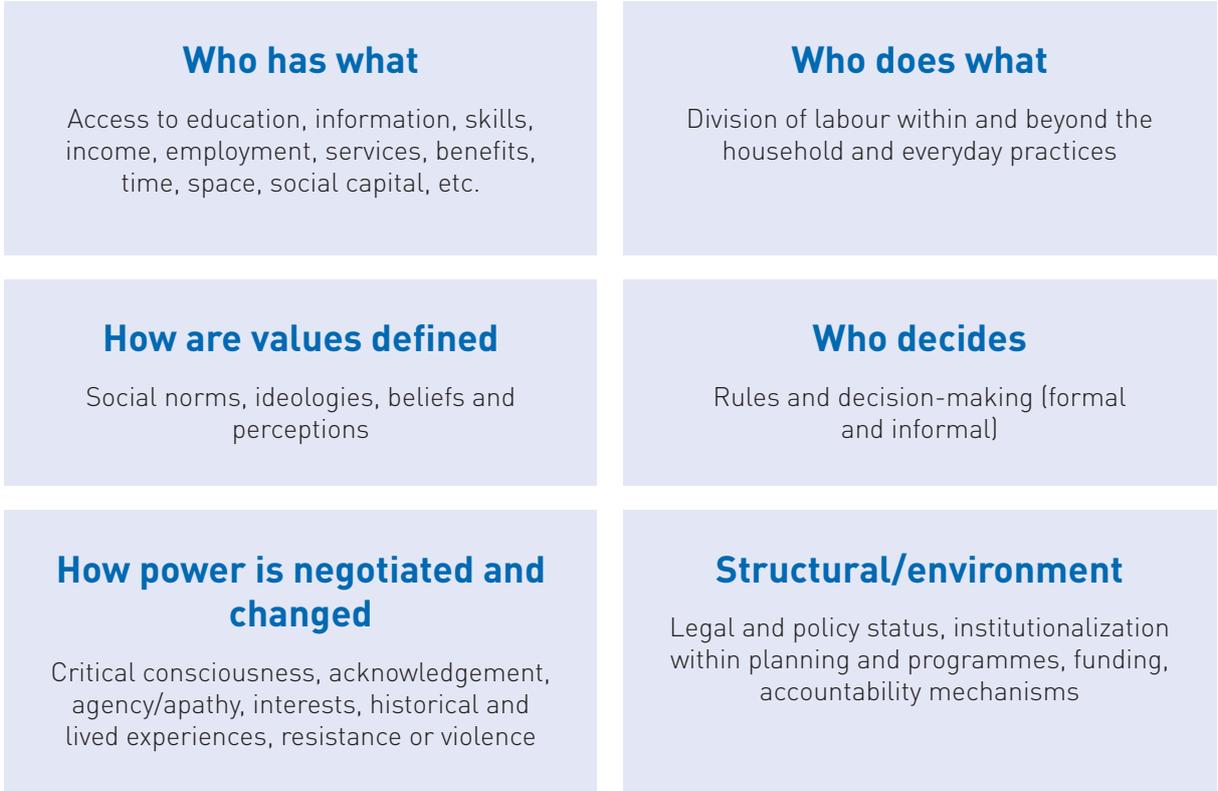
The above recommendations highlight areas in which international, national and local actors can have an impact on reducing the gender inequities caused by NTDs. Communities and frontline implementors should be supported to engage in programme development and adjustment to better understand and address local gendered needs related to NTDs. Case management approaches must consider the differing medical and psychosocial support needs of people of all genders affected by NTDs and their families and link them to appropriate gender-sensitive services. Training and supervision of health workers, volunteers and clinicians should be embedded within the primary health care system with support to critically understand, diagnose and act upon the gendered dimensions of NTDs and health. Furthermore, NTDs occur because people are continuously exposed to unsafe water, lack of adequate nutrition and are living in sub-standard conditions which stresses the need for a health system-based, multisectoral approach to programme delivery.<sup>[114]</sup>

By mainstreaming gender across sectors, the pledge to 'leave no one behind' and 'end the epidemic' of NTDs by 2030 will be more achievable and can contribute to the attainment of universal health coverage. If NTD programmes can reach people living in endemic areas through strengthening of health systems and engaging communities to achieve equitable and effective coverage by NTD preventive interventions and diagnostics and treatment, lessons could be learned which would help inform other health interventions and accelerate progress towards the attainment of universal health coverage and the Agenda 2030 in general.



# APPENDIX 1: APPLYING A GENDER FRAMEWORK TO UNDERSTAND HOW GENDER AS A POWER RELATION AND DRIVER OF INEQUALITY AFFECTS EXPOSURE, RISK OF TRANSMISSION, PREVENTION AND TREATMENT OF NEGLECTED TROPICAL DISEASES

A gender framework is required to better understand and act on the gendered dimensions of NTDs, understanding what, when and where women, girls, men and boys become infected by an NTD, how it manifests in these different groups and the responses they have to being ill. The gender framework proposed by Morgan and colleagues (2016) is useful to assess how the division of labour, bargaining power, access to resources and social norms, ideologies and beliefs of the different genders affect exposure, risk of transmission, prevention and treatment of NTDs.<sup>[75]</sup> This framework is situated around health and health systems development, is holistic in nature and can help researchers, policymakers and practitioners understand and address the gender power relations which are most relevant to NTD programmes.



Source: Adapted from Morgan et al. (2016).

# REFERENCES

1. Molyneux DH, Savioli L, Engels D: **Neglected tropical diseases: progress towards addressing the chronic pandemic.** *The Lancet* 2017, **389**:312–325.
2. Fitzpatrick C, Engels D: **Leaving no one behind: a neglected tropical disease indicator and tracers for the Sustainable Development Goals.** *Int Health* 2016, **8 Suppl 1**:i15–18.
3. Engels D, Daumerie D: **Investing to overcome the global impact of neglected tropical diseases: Third WHO report on neglected tropical diseases.** Geneva: World Health Organization's Department of Control of Neglected Tropical Diseases; 2013.
4. **Neglected Tropical Diseases** [[http://www.who.int/neglected\\_diseases/diseases/en/](http://www.who.int/neglected_diseases/diseases/en/)]
5. Mieras LF, Anand S, van Brakel WH, Hamilton HC, Martin Kollmann KH, Mackenzie C, Mason I, Wickenden A: **Neglected Tropical Diseases, Cross-Cutting Issues Workshop, 4–6 February 2015, Utrecht, the Netherlands: meeting report.** *Int Health* 2016, **8 Suppl 1**:i7–11.
6. Allotey P, Gyapong M: **The gender agenda in the control of tropical diseases: A review of current evidence.** World Health Organisation ed. Switzerland: Special Programme for Research & Training in Tropical Diseases (TDR); 2005.
7. Theobald S, MacPherson EE, Dean L, Jacobson J, Ducker C, Gyapong M, Hawkins K, Elphick-Pooley T, Mackenzie C, Kelly-Hope LA, et al: **20 years of gender mainstreaming in health: lessons and reflections for the neglected tropical diseases community.** *BMJ Global Health* 2017, **2**.
8. WHO: **Accelerating work to overcome the global impact of Neglected Tropical Diseases: A Roadmap for Implementation.** World Health Organisation; 2012.
9. Smith J, Taylor EM: **What Is Next for NTDs in the Era of the Sustainable Development Goals?** *PLOS Neglected Tropical Diseases* 2016, **10**:e0004719.
10. Aagaard-Hansen J, Chagnat CL: **Neglected tropical diseases: equity and social determinants.** In *Equity, social determinants and public health programmes.* Edited by Blas E, Kurup AS. Switzerland: World Health Organisation,; 2010: 135–159
11. Bhutta ZA, Sommerfeld J, Lassi ZS, Salam RA, Das JK: **Global burden, distribution, and interventions for infectious diseases of poverty.** *Infectious Diseases of Poverty* 2014, **3**:21.
12. Ackumey MM, Gyapong M, Pappoe M, Kwakye-Maclean C, Weiss MG: **Illness meanings and experiences for pre-ulcer and ulcer conditions of Buruli ulcer in the Ga-West and Ga-South Municipalities of Ghana.** *BMC Public Health* 2012, **12**:264.
13. Bangert M, Molyneux DH, Lindsay SW, Fitzpatrick C, Engels D: **The cross-cutting contribution of the end of neglected tropical diseases to the sustainable development goals.** *Infectious Diseases of Poverty* 2017, **6**:73.
14. Ramaiah KD, Das PK, Michael E, Guyatt H: **The economic burden of lymphatic filariasis in India.** *Parasitol Today* 2000, **16**:251–253.
15. Muela Ribera J, Peeters Grietens K, Toomer E, Hausmann-Muela S: **A Word of Caution against the Stigma Trend in Neglected Tropical Disease Research and Control.** *PLOS Neglected Tropical Diseases* 2009, **3**:e445.
16. Frick KD, Basilion EV, Hanson CL, Colchero MA: **Estimating the burden and economic impact of Trachomatous visual loss.** *Ophthalmic Epidemiology* 2003, **10**:121–132.
17. Bleakley H: **Disease and Development: Evidence from Hookworm Eradication in the American South.** *The quarterly journal of economics* 2007, **122**:73–117.
18. Ezeamama AE, McGarvey ST, Hogan J, Lapane KL, Bellinger DC, Acosta LP, Leenstra T, Olveda RM, Kurtis JD, Friedman JF: **Treatment for *Schistosoma japonicum*, Reduction of Intestinal Parasite Load, and Cognitive Test Score Improvements in School-Aged Children.** *PLOS Neglected Tropical Diseases* 2012, **6**:e1634.

19. World Health Organisation (WHO): **Working together for health – The World Health Report 2006.** 2006.
20. Hotez PJ: **Empowering Women and Improving Female Reproductive Health through Control of Neglected Tropical Diseases.** *PLoS Neglected Tropical Diseases* 2009, **3**:e559.
21. Baird S, Hicks JH, Kremer M, Miguel E: **Worms at Work: Long-run Impacts of a Child Health Investment.** *The Quarterly Journal of Economics* 2016, **131**:1637–1680.
22. Martha A, Bhushan A, Kasai T: **Taking sex and gender into account: An analytical framework.** Switzerland: World Health Organisation; 2011.
23. Vlassoff C, Moreno CG: **Placing gender at the centre of health programming: challenges and limitations.** *Social Science & Medicine* 2002, **54**:1713–1723.
24. Brabin L: **Factors affecting the differential susceptibility of males and females to onchocerciasis.** *Acta Leiden* 1990, **59**:413–426.
25. Gyapong M, Gyapong J, Weiss M, Tanner M: **The burden of hydrocele on men in Northern Ghana.** *Acta tropica* 2000, **77**:287–294.
26. **Gender, equity and human rights** [<http://www.who.int/gender-equity-rights/understanding/gender-definition/en/>]
27. Michelson EH: **Adam’s rib awry? Women and Schistosomiasis.** *Social Science & Medicine* 1993, **37**:493–501.
28. Short SE, Yang YC, Jenkins TM: **Sex, Gender, Genetics, and Health.** *American journal of public health* 2013, **103**:10.2105/AJPH.2013.301229.
29. Friedman JF, Mital P, Kanzaria HK, Olds GR, Kurtis JD: **Schistosomiasis and pregnancy.** *Trends Parasitol* 2007, **23**:159–164.
30. Nour NM: **Schistosomiasis: Health Effects on Women.** *Reviews in Obstetrics and Gynecology* 2010, **3**:28–32.
31. Rilkoﬀ H, Tukahebwa EM, Fleming FM, Leslie J, Cole DC: **Exploring Gender Dimensions of Treatment Programmes for Neglected Tropical Diseases in Uganda.** *PLoS Neglected Tropical Diseases* 2013, **7**:e2312.
32. World Health Organisation: **Report of the WHO Informal Consultation on the use of Praziquantel during Pregnancy/Lactation and Albendazole/Mebendazole in Children under 24 months.** Geneva; 2002.
33. World Health Organisation: **Report of the WHO Informal Consultation on the use of Praziquantel during Pregnancy/Lactation and Albendazole/Mebendazole in Children under 24 months.** Geneva: World Health Organisation, ; 2003.
34. McDonald MC: **Neglected tropical and zoonotic diseases and their impact on women’s and children’s health.** In *The Causes and Impacts of Neglected Tropical and Zoonotic Diseases: Opportunities for Integrated Intervention Strategies.* Washington: National Academies Press; 2011
35. Hotez PJ: **Empowering Girls and Women through Hookworm Prevention.** *The American Journal of Tropical Medicine and Hygiene* 2018, **98**:1211–1212.
36. Simon GG: **Impacts of neglected tropical disease on incidence and progression of HIV/AIDS, tuberculosis, and malaria: scientific links.** *International Journal of Infectious Diseases* 2016, **42**:54–57.
37. Bal M, Sahu PK, Mandal N, Satapathy AK, Ranjit M, Kar SK: **Maternal Infection Is a Risk Factor for Early Childhood Infection in Filariasis.** *PLoS Neglected Tropical Diseases* 2015, **9**:e0003955.
38. Cronin T, Sheppard J, de Wildt G: **Health-seeking behaviour for schistosomiasis: a systematic review of qualitative and quantitative literature.** *The Pan African medical journal* 2013, **16**.

39. **The sexual and reproductive health issue you've probably never heard of...**  
[<https://www.opendemocracy.net/5050/margaret-gyapong-sally-theobald/sexual-and-reproductive-health-issue-you%E2%80%99ve-probably-never-hear>]
40. Herricks JR, Hotez PJ, Wanga V, Coffeng LE, Haagsma JA, Basáñez M-G, Buckle G, Budke CM, Carabin H, Fèvre EM, et al: **The global burden of disease study 2013: What does it mean for the NTDs?** *PLoS Neglected Tropical Diseases* 2017, **11**:e0005424.
41. **Trachoma** [<http://www.who.int/news-room/fact-sheets/detail/trachoma>]
42. Huang YX, Manderson L: **The social and economic context and determinants of Schistosomiasis Japonica.** *Acta Trop* 2005, **96**:223–231.
43. Pinot de Moira A, Fulford AJC, Kabatereine NB, Ouma JH, Booth M, Dunne DW: **Analysis of Complex Patterns of Human Exposure and Immunity to Schistosomiasis mansoni: The Influence of Age, Sex, Ethnicity and IgE.** *PLoS Neglected Tropical Diseases* 2010, **4**:e820.
44. Kjetland EF, Leutscher PD, Ndhlovu PD: **A review of Female Genital Schistosomiasis.** *Trends Parasitol* 2012, **28**:58–65.
45. Stecher CW, Kallestrup P, Kjetland EF, Vennervald B, Petersen E: **Considering treatment of Male Genital Schistosomiasis as a tool for future HIV prevention: a systematic review.** *International Journal of Public Health* 2015, **60**:839–848.
46. **Schistosomiasis Epidemiological situation**
47. Kayuni SA, LaCourse EJ, Makaula P, Lampiao F, Juziwelo L, Fawcett J, Shaw A, Alharbi M, Verweij JJ, Stothard JR: **Case Report: Highlighting Male Genital Schistosomiasis (MGS) in Fishermen from the Southwestern Shoreline of Lake Malawi, Mangochi District.** *The American journal of tropical medicine and hygiene* 2019:tpmd190562.
48. Le L, Hsieh MH: **Diagnosing Urogenital Schistosomiasis: Dealing with Diminishing Returns.** *Trends in Parasitology* 2017, **33**:378–387.
49. Arakaki L, Kidane L, Kwan-Gett TS, Simpson S: **NEGLECTED TROPICAL DISEASES: WOMEN AND GIRLS IN FOCUS.** (CENTER S ed.: University of Washington School of Public Health and EquiACT; 2016.
50. Tanser F, Azongo DK, Vandormael A, Bärnighausen T, Appleton C: **Impact of the scale-up of piped water on urogenital schistosomiasis infection in rural South Africa.** *eLife* 2018, **7**:e33065.
51. Christinet V, Lazdins-Helds JK, Stothard JR, Reinhard-Rupp J: **Female Genital Schistosomiasis (FGS): from case reports to a call for concerted action against this neglected gynaecological disease.** *International Journal for Parasitology* 2016, **46**:395–404.
52. WHO: **Female Genital Schistosomiasis: A pocket atlas for clinical health-care professionals.** Switzerland: World Health Organisation; 2015.
53. Kukula VA, MacPherson EE, Tsey IH, Stothard JR, Theobald S, Gyapong M: **A major hurdle in the elimination of urogenital schistosomiasis revealed: Identifying key gaps in knowledge and understanding of female genital schistosomiasis within communities and local health workers.** *PLoS Neglected Tropical Diseases* 2019, **13**:e0007207.
54. Musuva RM, Awiti A, Omedo M, Ogutu M, Secor WE, Montgomery SP, Alaii J, Mwinzi PN: **Community knowledge, attitudes and practices on Schistosomiasis in western Kenya--the SCORE Project.** *Am J Trop Med Hyg* 2014, **90**:646–652.
55. Ahlberg BM, Mwangi R, Poggensee G, Feldmeier H, Krantz I: **'Better infection than hunger'. A study of illness perceptions with special focus on Urinary Schistosomiasis in Northern Tanzania.** *African Sociological Review / Revue Africaine de Sociologie* 2003, **7**:18–34.
56. Mbabazi PS, Andan O, Fitzgerald DW, Chitsulo L, Engels D, Downs JA: **Examining the Relationship between Urogenital Schistosomiasis and HIV Infection.** *PLoS Neglected Tropical Diseases* 2011, **5**:e1396.

57. Ghoneim MA: **Bilharziasis of the genitourinary tract.** *BJU International* 2002, **89**:22–30.
58. Dawaki S, Al-Mekhlafi HM, Ithoi I, Ibrahim J, Abdulsalam AM, Ahmed A, Sady H, Atroosh WM, Al-Areeqi MA, Elyana FN: **Prevalence and risk factors of schistosomiasis among hausa communities in Kano state, Nigeria.** *Revista do Instituto de Medicina Tropical de São Paulo* 2016, **58**.
59. Parker M, Allen T: **Does mass drug administration for the integrated treatment of neglected tropical diseases really work? Assessing evidence for the control of Schistosomiasis and Soil-transmitted Helminths in Uganda.** *Health Research Policy and Systems* 2011, **9**:3.
60. Ejike CU, Oluwole AS, Mogaji HO, Adeniran AA, Alabi OM, Ekpo UF: **Development and testing of Schisto and Ladders™, an innovative health educational game for control of schistosomiasis in schoolchildren.** *BMC research notes* 2017, **10**:236.
61. Kassar ASA: **Effect of Integrated School Program in Control of Urinary Schistosomiasis among Basic Schools Children in Elrahad Town, Elrahad Locality, North Kordofan State, Sudan (2014–2017).** University of Gezira, 2017.
62. Manderson L, Aagaard-Hansen J, Allotey P, Gyapong M, Sommerfeld J: **Social Research on Neglected Diseases of Poverty: Continuing and Emerging Themes.** *PLoS Neglected Tropical Diseases* 2009, **3**:e332.
63. Du RY, Stanaway JD, Hotez PJ: **Could violent conflict derail the London Declaration on NTDs?** *PLoS Neglected Tropical Diseases* 2018, **12**:e0006136.
64. Mbah MLN, Poolman EM, Drain PK, Coffee MP, van der Werf MJ, Galvani AP: **HIV prevalence correlates with Schistosoma haematobium in sub-Saharan Africa.** *Tropical medicine & international health : TM & IH* 2013, **18**:1174–1179.
65. Al-Kamel MA: **Impact of leishmaniasis in women: a practical review with an update on my ISD-supported initiative to combat leishmaniasis in Yemen (ELYP).** *International Journal of Women's Dermatology* 2016, **2**:93–101.
66. Hotez PJ, Bottazzi ME, Franco-Paredes C, Ault SK, Periago MR: **The Neglected Tropical Diseases of Latin America and the Caribbean: A Review of Disease Burden and Distribution and a Roadmap for Control and Elimination.** *PLoS Neglected Tropical Diseases* 2008, **2**:e300.
67. Mackey TK, Liang BA, Cuomo R, Hafen R, Brouwer KC, Lee DE: **Emerging and reemerging neglected tropical diseases: a review of key characteristics, risk factors, and the policy and innovation environment.** *Clinical microbiology reviews* 2014, **27**:949–979.
68. Coutinho EM, Abath FG, Barbosa CS, Domingues AL, Melo MC, Montenegro SM, Lucena MA, Romani SA, Souza WV, Coutinho AD: **Factors involved in Schistosoma mansoni infection in rural areas of northeast Brazil.** *Mem Inst Oswaldo Cruz* 1997, **92**:707–715.
69. Dujardin J-C, Campino L, Cañavate C, Dedet J-P, Gradoni L, Soteriadou K, Mazeris A, Ozbel Y, Boelaert M: **Spread of vector-borne diseases and neglect of Leishmaniasis, Europe.** *Emerging infectious diseases* 2008, **14**:1013–1018.
70. Altizer S, Ostfeld RS, Johnson PTJ, Kutz S, Harvell CD: **Climate Change and Infectious Diseases: From Evidence to a Predictive Framework.** *Science* 2013, **341**:514–519.
71. Martens WJM, Jetten TH, Rotmans J, Niessen LW: **Climate change and vector-borne diseases: A global modelling perspective.** *Global Environmental Change* 1995, **5**:195–209.
72. Fuhrimann S, Winkler MS, Kabatereine NB, Tukahebwa EM, Halage AA, Rutebemberwa E, Medlicott K, Schindler C, Utzinger J, Cissé G: **Risk of Intestinal Parasitic Infections in People with Different Exposures to Wastewater and Fecal Sludge in Kampala, Uganda: A Cross-Sectional Study.** *PLoS Neglected Tropical Diseases* 2016, **10**:e0004469.
73. Dean L, Page S, Hawkins K, Stothard R, Thomson R, Wanji S, Gyapong M, Anagbogu I, Molyneux D, Theobald S: **Tailoring mass drug administration to context: implementation research is critical in achieving equitable progress in the control and elimination of helminth neglected tropical diseases in sub-Saharan Africa.** *International Health* 2016, **8**:233–234.

74. **Ghana Health Service 2014 Annual Report** [[http://www.ghanahealthservice.org/downloads/Ghana\\_Health\\_Service\\_2014\\_Annual\\_Report.pdf](http://www.ghanahealthservice.org/downloads/Ghana_Health_Service_2014_Annual_Report.pdf)]
75. Gyapong JO: **An Overview of Neglected Tropical Diseases in Sub-Saharan Africa**. In *Neglected Tropical Diseases – Sub-Saharan Africa*. Edited by Gyapong J, Boatman B. Cham: Springer International Publishing; 2016: 1–14
76. Sen G, Östlin P: **Unequal, unfair, ineffective and inefficient: Gender inequity in health – Why it exists and how we can change it. Final report to the WHO Commission on social determinants of health**. Stockholm: Karolinska Institute,; 2007.
77. Simpson S: **Towards universal coverage for preventive chemotherapy for Neglected Tropical Diseases: guidance for assessing “who is being left behind and why”: WORKING DRAFT FOR FURTHER PILOTING DURING 2018 – 2019**. World Health Organisation; 2017.
78. Morgan R, George A, Ssali S, Hawkins K, Molyneux S, Theobald S: **How to do (or not to do)... gender analysis in health systems research**. *Health Policy Plan* 2016, **31**:1069–1078.
79. Debacker M, Aguiar J, Steunou C, Zinsou C, Meyers WM, Scott JT, Dramaix M, Portaels F: **Mycobacterium ulcerans disease: role of age and gender in incidence and morbidity**. *Tropical Medicine & International Health* 2004, **9**:1297–1304.
80. Upadhyayula SM, Mutheneni SR, Kadiri MR, Kumaraswamy S, Nagalla B: **A Cohort Study of Lymphatic Filariasis on Socio Economic Conditions in Andhra Pradesh, India**. *PLoS ONE* 2012, **7**:e33779.
81. Chesnais CB, Missamou F, Pion SD, Bopda J, Louya F, Majewski AC, Fischer PU, Weil GJ, Boussinesq M: **A case study of risk factors for lymphatic filariasis in the Republic of Congo**. *Parasites & Vectors* 2014, **7**:300–300.
82. Wanji S, Kengne-Ouafo JA, Esum ME, Chounna PWN, Adzemye BF, Eyong JEE, Jato I, Datchoua-Poutcheu FR, Abong RA, Enyong P, Taylor DW: **Relationship between oral declaration on adherence to ivermectin treatment and parasitological indicators of onchocerciasis in an area of persistent transmission despite a decade of mass drug administration in Cameroon**. *Parasites & Vectors* 2015, **8**:667.
83. Campbell SJ, Nery SV, McCarthy JS, Gray DJ, Soares Magalhães RJ, Clements ACA: **A Critical Appraisal of Control Strategies for Soil-Transmitted Helminths**. *Trends in Parasitology* 2016, **32**:97–107.
84. Krentel A, Fischer PU, Weil GJ: **A Review of Factors That Influence Individual Compliance with Mass Drug Administration for Elimination of Lymphatic Filariasis**. *PLOS Neglected Tropical Diseases* 2013, **7**:e2447.
85. Najafizada SAM, Labonté R, Bourgeault IL: **Community health workers of Afghanistan: a qualitative study of a national program**. *Conflict and Health* 2014, **8**:26.
86. Hoodfar H: **Activism under the radar: Volunteer women health workers in Iran**. In *Middle East Report*, vol. 250; 2009.
87. Vouking MZ, Tamo VC, Tadenfok CN: **Contribution and performance of female community-directed distributors in the treatment of onchocerciasis with ivermectin in Sub-Saharan Africa: a systematic review**. *Pan African Medical Journal* 2015, **20**.
88. Lehmann U, Friedman I, Sanders D: **Review of The Utilisation And Effectiveness Of Community-Based Health Workers In Africa**. University of the Western Cap: World Health Organisation; 2004.
89. John AS, Rao PS, Das S: **Assessment of needs and quality care issues of women with leprosy**. *Lepr Rev* 2010, **81**:34–40.
90. Courtright P, Lewallen S: **Why are we addressing gender issues in vision loss?** *Community Eye Health* 2009, **22**:17–19.
91. Bandyopadhyay L: **Lymphatic filariasis and the women of India**. *Soc Sci Med* 1996, **42**:1401–1410.

92. Vlassoff C, Bonilla E: **Gender-related differences in the impact of tropical diseases on women: what do we know?** *J Biosoc Sci* 1994, **26**:37–53.
93. DIJKSTRA JIR, VAN BRAKEL W, H., VAN ELTEREN M: **Gender and leprosy-related stigma in endemic areas: A systematic review.** *Lepr Rev* 2017, **88**:419–440.
94. Dunn C, Callahan K, Katarbarwa M, Richards F, Hopkins D, Withers PC, Jr., Buyon LE, McFarland D: **The Contributions of Onchocerciasis Control and Elimination Programs toward the Achievement of the Millennium Development Goals.** *PLoS Neglected Tropical Diseases* 2015, **9**:e0003703.
95. Person B, Bartholomew LK, Gyapong M, Addiss DG, van den Borne B: **Health-related stigma among women with lymphatic filariasis from the Dominican Republic and Ghana.** *Social Science & Medicine* 2009, **68**:30–38.
96. Price VG: **Factors preventing early case detection for women affected by leprosy: a review of the literature.** *Glob Health Action* 2017, **10**:1360550.
97. Person B, Addiss D, Bartholomew LK, Meijer C, Pou V, González G, Van Den Borne B: **“Can It Be That God Does Not Remember Me”: A Qualitative Study on the Psychological Distress, Suffering, and Coping of Dominican Women With Chronic Filarial Lymphedema and Elephantiasis of the Leg.** *Health Care for Women International* 2008, **29**:349–365.
98. Hess RF, Ross R, Gililland Jr JL: **Infertility, Psychological Distress, and Coping Strategies among Women in Mali, West Africa: A Mixed-Methods Study.** *Afr J Reprod Health* 2018, **22**:60–72.
99. Engelman D, Fuller LC, Solomon AW, McCarthy JS, Hay RJ, Lammie PJ, Steer AC: **Opportunities for integrated control of neglected tropical diseases that affect the skin.** *Trends in parasitology* 2016, **32**:843–854.
100. Cassidy T, Worrell CM, Little K, Prakash A, Patra I, Rout J, Fox LM: **Experiences of a Community-Based Lymphedema Management Program for Lymphatic Filariasis in Odisha State, India: An Analysis of Focus Group Discussions with Patients, Families, Community Members and Program Volunteers.** *PLoS Neglected Tropical Diseases* 2016, **10**:e0004424.
101. Litt E, Baker MC, Molyneux D: **Neglected tropical diseases and mental health: a perspective on comorbidity.** *Trends Parasitol* 2012, **28**:195–201.
102. Weiss MG: **Stigma and the Social Burden of Neglected Tropical Diseases.** *PLoS Neglected Tropical Diseases* 2008, **2**:e237.
103. Kabatereine NB, Malecela M, Lado M, Zaramba S, Amiel O, Kolaczinski JH: **How to (or Not to) Integrate Vertical Programmes for the Control of Major Neglected Tropical Diseases in Sub-Saharan Africa.** *PLoS Neglected Tropical Diseases* 2010, **4**:e755.
104. Cavalli A, Bamba SI, Traore MN, Boelaert M, Coulibaly Y, Polman K, Pirard M, Van Dormael M: **Interactions between Global Health Initiatives and Country Health Systems: The Case of a Neglected Tropical Diseases Control Program in Mali.** *PLoS Neglected Tropical Diseases* 2010, **4**:e798.
105. Cairncross S, Muller R, Zagaria N: **Dracunculiasis (Guinea worm disease) and the eradication initiative.** *Clinical microbiology reviews* 2002, **15**:223–246.
106. Johnston EA, Teague J, Graham JP: **Challenges and opportunities associated with neglected tropical disease and water, sanitation and hygiene intersectoral integration programs.** *BMC Public Health* 2015, **15**:547.
107. Boisson S, Engels D, Gordon BA, Medlicott KO, Neira MP, Montresor A, Solomon AW, Velleman Y: **Water, sanitation and hygiene for accelerating and sustaining progress on neglected tropical diseases: a new Global Strategy 2015–20.** *International health* 2016, **8 Suppl 1**:i19–i21.
108. **A Summary of the Neglected Tropical Disease Policy Context in Nigeria** [[https://countdown.lstmed.ac.uk/sites/default/files/content/centre\\_page/attachments/policy\\_summary\\_final.pdf](https://countdown.lstmed.ac.uk/sites/default/files/content/centre_page/attachments/policy_summary_final.pdf)]

109. Ozano K, Simkhada P, Thann K, Khatri R: **Improving local health through community health workers in Cambodia: challenges and solutions.** *Human Resources for Health* 2018, **16**:2.
110. Noblick J, Skolnik R, Hotez PJ: **Linking Global HIV/AIDS Treatments with National Programs for the Control and Elimination of the Neglected Tropical Diseases.** *PLOS Neglected Tropical Diseases* 2011, **5**:e1022.
111. Harms G, Feldmeier H: **Review: HIV infection and tropical parasitic diseases – deleterious interactions in both directions?** *Tropical Medicine & International Health* 2002, **7**:479–488.
112. **Bilharzia and HIV (BILHIV): The BILHIV study aims to explore the innovative role of self-swabs for the diagnosis of female genital schistosomiasis and its association with HIV transmission.** [<https://www.lshtm.ac.uk/node/76621>]
113. Hotez PJ, Fenwick A, Kjetland EF: **Africa’s 32 Cents Solution for HIV/AIDS.** *PLOS Neglected Tropical Diseases* 2009, **3**:e430.
114. De Maio F: **Neglected Tropical Diseases.** In *Global Health Inequities: A Sociological Perspective.* Macmillan International Higher Education; 2014







THE ACCESS AND  
DELIVERY PARTNERSHIP

*New Health Technologies for TB, Malaria and NTDs*

[www.undp.org](http://www.undp.org)  
[www.adphealth.org](http://www.adphealth.org)  
@ADP\_health

**COUNTDOWN**  
Calling time on Neglected Tropical Diseases

**TDR** For research on  
diseases of poverty  
UNICEF • UNDP • World Bank • WHO



From the People of Japan



*Empowered lives.  
Resilient nations.*